



## Committee for Rare Diseases within the UN - CfRD



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# Work within the UN world

- Ordinary United Nation – consist of member states
- ECOSOC within UN – consist of NGO supported by member states
- UN organizations – 11 broad programs and funds like UNDP, 15 specialized agencies like WHO, UNESCO, IMF, 7 other entities and organizations.
- CoNGO – hundreds of full members who are NGO with a consultative status at UN.
- CoNGO work through their 34 Committees

# Vision, Mission and Objectives of CoNGO

## VISION

- CONGO's vision is to be the primary support and platform for a civil society represented by a global community of informed, empowered and committed NGOs that fully participate with the UN in decision-making and programs leading to a better world, a world of economic and social justice.

## MISSION

- Facilitate through various means the development of a dynamic and informed world-wide NGO community able to influence policies and actions at all levels of the United Nations.

# OBJECTIVES

- A. Improve NGOs accessibility and presence at all levels of the United Nations
- B. Enhance the effective engagement of NGOs with the United Nations
- C. Strengthen the dialogue between the United Nations and Non-governmental organizations
- D. Engage NGOs to work together on issues of common interest
- E. Education / Capacity Development
- F. Work in partnership with UN civil society focal points
- G. Advocate on the Principles and Goals that NGOs and United Nations share

# Facts

- CoNGO consists of full and ass. Members
- Full members are NGO who have a consultative status within the UN.
- CoNGO work through their Committees
- To set up a Committee you need the support of at least 20 full members of CoNGO
- Committee for Rare Disease was put forward by Agrenska Foundation (who are a full member of CoNGO, and have special consultative status within ECOSOC and the UN) and approved by 37 full members last year at the AGM for CoNGO.
- The CfRD can be operated by an consortium of NGO and other organizations, as well as companies. But only full member have a vote at CoNGO.



# Procedure – how to move on from here

- Declaration at the RDI meeting in Madrid May 28<sup>th</sup>
- Internal work preparing draft for by-laws, and organization for CfRD, in Bxl June 16<sup>th</sup>
- Meeting with CoNGO's President Cyril Richie in New York at CoNGO headquarter, where we also invite other members of CoNGO to listen to our plans and for their support, in NY October week 43
- Launching the CfRD in NY in the UN building at ECOSOC's premises, in March or April 2016

# Dates and place

- Madrid – May 28<sup>th</sup> 2015
- Brussels – June 16<sup>th</sup> 2015
- New York – October 19<sup>th</sup> 20<sup>th</sup> or 21<sup>st</sup> 2015
- New York – March or April 2016

# Welcome to the world of United Nations

